

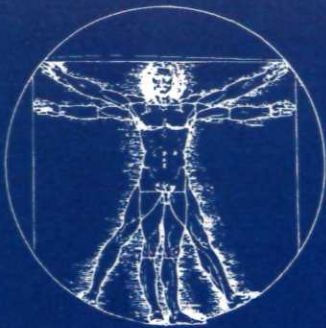
Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Spring 1993

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MID-ATLANTIC ETHICS COMMITTEE

N E W S L E T T E R

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Institutional Ethics Committee Resource Network
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Inside this issue:

State News

Maryland Health Care Decision Act Passed ..	1
Washington, D.C.--Tuberculosis Issues	4
Network News	2
A New Concept: Government Ethics Committees	5
Case Consultation	6
Case Comments:	
From a Law Professor	7
From a Bioethicist	8
Implementing the PSDA: Some Reactions	9
Nurses' Perspectives on Their Role to Implement The PSDA	9
Implementation of the PSDA in Nursing Homes	9
Courses in Bioethics	10
Calendar of Events	10

STATE NEWS

MARYLAND HEALTH CARE DECISION ACT PASSED BY LEGISLATURE

Shortly before the Maryland legislative session came to a close on April 12th, the legislature passed the "Health Care Decision Act." The legislation was modeled after a proposal drafted by a coalition of consumer and provider representatives and spear-headed by Diane Hoffmann from the University of Maryland School of Law; Judge John Fader from the Baltimore County Circuit Court, Leslie Fried and Joan O'Sullivan of the Legal Aid Bureau and Gerry Miller and Martin Milrod of the Maryland Chapter of the AARP. The proposal was largely based on Virginia's Health Care Decision Act but was modified during the legislative session to reflect the views of a number of individuals and groups who submitted suggested amendments to the Senate Judicial Proceedings Committee and the House Environmental Matters Committee. The Governor is expected to sign the legislation in May and it will take effect on October 1, 1993. A summary of the key elements of the new law follows.

Letter From the Editor

Our cover story in this issue describes Maryland's new Health Care Decision Act. It is a landmark piece of legislation passed this session by the Maryland legislature. The new law, if signed by the Governor, will take effect October 1, 1993. It provides greater decision-making authority for families and health care providers in making health care decisions for patients who lack capacity to make informed choices. The Act has a number of unique features that are described in the article. Other stories in this issue include summaries of two studies on the implementation of the Patient Self Determination Act and a description of a new type of ethics committee at a county Department of Social Services. We hope you enjoy the issue.

Diane E. Hoffmann, Editor

ADVANCE DIRECTIVES

The Act allows a competent adult to deal with future health care issues by one or more of the following three methods:

(1) written instructions authorizing the provision, withholding, or withdrawal of health care

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NETWORK NEWS

Baltimore Area Ethics Committee Network

The first meeting of the year was held on February 11th at Good Samaritan Hospital. The topic was "The First Year of the Patient Self-Determination Act: Sharing Experiences and Impressions." Attendance was excellent and included visitors from as far as northern Virginia. A number of individuals present had actually collected data on several aspects of the implementation of the Act at their facility. Summaries of two studies appear in the newsletter (pp. 9-10). The overall reaction of those attending seemed to be that the Act has not achieved an important objective -- having physicians talk to patients about advance directives and their wishes regarding various types of medical interventions should they become incapacitated. Instead, it seems that the Act has pushed the information dissemination and any related discussion onto administrative personnel.

The second meeting of the Network this year was held on April 1st at Sinai Hospital. The topic was determining patient competency. Dr. Robert Roca from Francis Scott Key Hospital discussed two cases which came to an ethics committee at one institution where a question was raised about the patient's competency. The cases raised a number of questions such as whether or not it is appropriate for an ethics committee to get involved in cases where the competence of the patient is the primary issue; how certain we need to be about a patient's decision-making capacity; whether the concept of a "sliding scale" of competency makes sense; and how to deal with providers who may be raising an issue about the capacity of the patient solely because the patient disagrees with the provider's recommendation for medical intervention.

The next meeting of the Network will be on June 3rd at University of Mary-

land Medical System. The topic will be "Making Health Care Decisions for Infants and Children." Anyone interested is welcome to attend. For more information contact Henry Silverman, 706-6250 or Diane Hoffmann, 706-7191.

Washington Metropolitan BioethicsNetwork (WMBN)

In February, the WMBN met at Potomac Hospital in Woodbridge, VA. Sr. Carol Taylor spoke on the topic: To Feed or Not to Feed: The Ethical Dilemmas. The highlights of the meeting and her remarks appear on page 4. On March 23rd, the WMBN met at Children's Hospital. The topic was "Ethics Committees Working Together." At the meeting, Jacqueline Glover, Ph.D., discussed a case that came to the Ethics Committee of Montgomery County Department of Social Services and the collaboration between the County Committee and the Committee at Children's Hospital. The Montgomery County Committee is one of the only ethics committees of its kind in the country. Dr. Jay Kenney describes the evolution and activities of that committee in an article on page 5 of the Newsletter.

The April meeting of the Network was held on April 17th at the Lisner-Louise-Dickson Home in Northwest D.C. Vera Mayer, Ombudsman for Iona Senior Services coordinated the program, "Beyond Substituted Judgment and Best Interest: What Constitutes Ethical Care of the Decisionally Impaired?" Edward Howe, M.D., J.D., led a discussion on the topic.

The next WMBN meeting will be on May 25th. Gail Mott from Hospice Care of D.C. is planning a session on religious issues in bioethics. Contact Joan Lewis at (202)682-1581 for more information.

Cont. on page 4

STATE NEWS

Maryland Health Care Decisions Act Passed

Cont. from page 1

(2) a written appointment of an agent to make health care decisions for the patient; and

(3) an oral statement to a physician leaving instructions or appointing an agent.

Formalities: Written advance directives must be witnessed by two witnesses. (Neither witness may be the person's health care agent. At least one witness may not have a financial interest in the person's death). Oral Advance directives must be made to a physician and witnessed by one individual; must be recorded in the patient's medical record and signed and dated by the physician and the witness.

Limitation on Agents: A health care agent may not be an employee, owner or operator of a health care facility where the patient is being treated, unless the agent would also qualify as a surrogate.

Forms - Although individuals may prepare their own documents worded as they choose, the Act includes two optional forms: (1) a more traditional *living will form* allowing individuals to state whether they want life sustaining treatment provided, withheld or withdrawn if they are either terminally ill or in a persistent vegetative state; and (2) a broader *advance directive form* allowing individuals to appoint a health care agent, leave instructions for any type of medical care or both. Using the advance directive, individuals may specify whether they want life sustaining treatment if they are terminally ill, in a persistent vegetative state or have an end stage condition.

End Stage Condition, a unique concept in the law, is defined as *an advanced, progressive, irreversible condition caused by injury, disease or illness:*

(1) *that has caused severe and permanent deterioration indicated by incompetency and complete physical dependency; and*

(2) *for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.*

Both forms allow individuals to make a specific decision regarding the provision, withholding or withdrawal of artificial nutrition and hydration. Both forms also allow an individual to direct that all available medical treatment be given in accordance with accepted health care standards.

SURROGATE DECISION-MAKING

If a patient has not picked a health care agent and is no longer able to make health care decisions personally, a surrogate may do so. Surrogates are listed in priority order; individuals in a particular class may be consulted only if all individuals in the next higher class are unavailable: (1) a guardian, if one has been appointed; (2) the patient's spouse; (3) an adult child of the patient; (4) a parent of the patient; (5) an adult brother or sister of the patient; or (6) a friend or relative who specifies in writing that he or she is a close friend of the patient and provides facts to demonstrate enough regular contact with the patient so as to make the surrogate familiar with the patient's activities, health and personal beliefs.

Disputes Among Surrogates of Same Class:

- A health care provider must refer these disputes to a patient care advisory committee. The patient's physician may follow the recommendation of the committee without risking liability for suits based on lack of consent or authorization.

Standards for surrogates: Both health care agents and surrogates must make a decision that is consistent with the patient's wishes (sometimes called the "substituted judgment" standard) or, if those wishes are unknown or unclear,

what is in the patient's best interests. Factors for the surrogate to consider in determining the patient's wishes are listed and a definition of "best interest" is provided.

Limits on Surrogate

Decisionmaking: A surrogate may authorize the withholding or withdrawal of life-sustaining procedures only if two physicians certify, to a reasonable degree of medical certainty, that the patient has a terminal or end stage condition or is in a persistent vegetative state. A surrogate may not consider a patient's pre-existing, long term medical or physical disability in making a decision to withhold or withdraw life sustaining treatment.

PATIENT SAFEGUARDS

A health care provider who believes that an instruction to withhold or withdraw life sustaining procedures from a patient is inconsistent with generally accepted standards of patient care must petition a patient care advisory committee or file a petition in court.

Family members and qualified surrogates may file suit to enjoin allegedly unlawful actions. These cases are to be given expedited consideration by the courts.

A person loses immunity for decisions involving life-sustaining procedures if the person did not comply with the Act in good faith.

Mercy killing and euthanasia are prohibited. Criminal penalties are provided for destruction, concealment, forgery and the like of an advance directive document.

MEDICALLY INEFFECTIVE TREATMENT

Except in certain situations pending the transfer of a patient, a physician need not provide treatment the physician believes to be medically ineffective or ethically inappropriate. **Medically ineffective treatment** is defined

Cont. on page 4

STATE NEWS

Maryland Health Care Decisions Act Passed

Cont. from page 3

as treatment that, to a reasonable degree of medical certainty, will neither prevent or reduce the deterioration of the health of an individual nor prevent the impending death of an individual.

TRANSFER OF PATIENT

If a health care provider intends not to comply with the instruction of a surrogate or agent, the provider must inform the person giving the instruction of that decision and inform the person that they may request a transfer to another health care provider; and assist, if desired, in effectuating the transfer.

Pending the transfer, a health care provider must comply with the request for treatment of a competent patient, surrogate or agent if failure to comply would result in the death of the patient.

IMMUNITY

Health care providers who take actions based on authority set out in the Act are immune from claims that the actions were unauthorized. Health care agents and surrogates who follow the Act when they authorize the withholding or withdrawal of life-sustaining procedures are immune from liability.

OUTPATIENT DNRs

The Act authorizes emergency medical personnel to follow "do not resuscitate" (DNR) orders in the outpatient setting based on protocols established by the Maryland Institute for Emergency Medical Services Systems in conjunction with the State Board of Physician Quality Assurance.

STANDARDS FOR GUARDIANS AND COURTS

The Act provides that in making decisions about life-sustaining procedures for incapacitated patients who are under guardianship, judges must base decisions on the substituted judgment and best interest tests. It also codifies a

"clear and convincing evidence" standard for the application of these tests.

The comprehensive legislation is part of a new trend in this area to consolidate living will, durable power of attorney and surrogate decision-making into a single bill. From a national perspective the law has several unique aspects; specifically, the end stage condition category and the inclusion of definitions of medically ineffective treatment and best interest.

WASHINGTON, D.C. TUBERCULOSIS -- A NEW ISSUE FOR ETHICS COMMITTEES?

The District of Columbia is facing an increase in the number of tuberculosis patients, many of them homeless and many of them with HIV. This has triggered several ethical questions for hospitals who treat these patients.

The first problem comes after a hospital completes inpatient treatment of a homeless TB patient and he/she is no longer infectious, but must continue taking oral medication for 6-18 months or so. Homeless shelters are concerned about these patients since if they do not continue on their medication, they can become reinfected and can infect other shelter residents.

The second problem is when a hospitalized patient elects to leave the hospital against medical advice. Such a patient returns to the street often to find drugs, and then may return to the hospital emergency room. Or the patient leaves and goes back to a familiar shelter. In either case, the patient runs the risk of infecting many others.

What are the patient's rights under these types of circumstances? How can TB patients be required to continue medication? Can his/her autonomy be challenged in order to protect the societal good? Can the District adopt legislation which detains infectious TB patients? Can hospitals set up locked units for infectious TB patients? Can

homeless shelters keep out TB patients even if they are no longer infectious, but might become so? In an attempt to address these issues, a working group comprised of representatives of Health Care for the Homeless, the District of Columbia Hospital Association, the Medical Society of the District of Columbia, the Commission of Public Health, and D. C. General Hospital has developed a proposal for a respite care center for homeless TB patients. At this time, the proposal, which calls for approximately \$1 million in funding for such a center on the grounds of D.C. General Hospital, has not been approved by the Council of the District of Columbia. It does, however, have the support of the Council Chairman and the Department of Human Services. Efforts may be made to try to include the plan in the 1994 budget after the start of the District's fiscal year in October.

Submitted by Joan Lewis

NETWORK NEWS

Cont. from page 2

To Feed or Not to Feed: The Ethical Dilemmas

In February, the Washington Metropolitan Bioethics Network held a meeting on the topic of feeding patients. The purpose of the session was to explore the broad range of ethical issues that surround nutrition and hydration questions and to provide a systematic framework to facilitate clinical decisionmaking. The following general ethical guidelines were presented for withholding and withdrawing nutrition and hydration. Nutrition and hydration **may be withheld or withdrawn** when this treatment is 1) **ineffective** (i.e., there is a medical determination of physiologic futility; many would argue assisted nutrition must be terminated once this is determined), or 2) when the **burdens outweigh the benefits** (this is a subjective determination which can only be made by the patient or a valid

surrogate familiar with the patient's values and interests). The Lynn and Childress "inappropriate reasons for providing food and fluids" were reviewed: 1) the obligation to provide "ordinary" care, 2) the obligation to continue treatments once started, 3) the obligation to avoid being the unambiguous cause of death; and 4) the obligation to provide symbolically significant treatment.¹

Five clinical situations in which nutritional support questions frequently present were then explored: dehydration in the terminally ill patient; withdrawing nutrition and hydration once a diagnosis of persistent vegetative state is made; and making feeding decisions for patients in progressive stages of dementia and patients with acute or chronic illnesses who are not in danger of imminent death and choose to forego feeding (those who are physically unable to eat as well as those able to eat). Summary guidelines from this discussion follow:

If a person is physically unable to ingest food and fluids, the provision of artificial nutrition and hydration constitutes a morally optional medical treatment whose use is to be determined by the patient, or if the patient lacks decisionmaking capacity, by his or her morally valid surrogate on the basis of the patient's wishes or a benefit/burden ratio.

If an acutely or chronically ill patient is physically able to ingest food and fluids but chooses not to, the obligations of health care professionals are first to ensure that this is an informed, voluntary choice (e.g., identify and treat reversible depression, educate) and second to make a careful choice about whether or not to continue to offer feedings as appropriate. The interdisciplinary team should coordinate a plan of care which either respects and supports the patient's choice or continues to challenge the choice. Initiating artificial nutrition and hydration when the patient becomes too weak to protest violates the patient's autonomy. While many health care professionals respect the right of

competent patients to voluntarily choose to terminate their lives by not eating and drinking, they find a patient's attempt to secure their support for this refusal an offer to participate in suicide. While some professionals may reconcile assisted suicide with their personal and professional moral sense, others may refuse to cooperate on the grounds that this violates both their personal and professional moral integrity. Some would also argue that rational suicide does not exist and would attempt to secure counseling and treatment for the patient.

Following this presentation an hour of shared comments, questions and answers from the floor evidenced the lack of agreement among clinicians about the most basic of questions, e.g., is the provision of artificial nutrition and hydration a medical treatment like ventilatory support and dialysis or is it symbolic of the basic human care everyone is owed. Despite consensus in professional literature, law, policy, and regulation about the provision of nutrition and hydration, the issue is far from resolved for clinicians struggling to make everyday decisions at the bedside.²

Submitted by
Carol Taylor, MSN
PhD Candidate
Georgetown University Center for
Clinical Bioethics

¹Lynn, J., & Childress, J.F. (1983). *Must patients always be given food and water.* *Hastings Center Report*, 10, 17-21.

²Solomon, M.Z., et al. (1993). *Decisions near the end of life; professional views on life-sustaining treatments.* *American Journal of Public Health*, 83(1), 14-21.

A NEW CONCEPT: GOVERNMENT ETHICS COMMITTEES

Background

In the Spring of 1991, the Montgomery County Department of Social Services (MCDSS) initiated action to establish a formal ethics review process. The Department Director, serving as guardian of the person for individuals under the age of sixty who are unable to make decisions in their own behalf as well as children where parental rights have been terminated, was faced with making recommendations in a number of cases involving serious and complex ethical issues in patient care. Examples included: consenting to a Do Not Resuscitate Order (DNR) for an elderly woman, allowing experimental psychotropic medication for an adult schizophrenic woman, granting permission for HIV testing of a sexually active, young adult male, and consenting to major body altering surgery for an older woman in absence of written advanced directives.

Ann Bishop, Department Director, along with Jay Kenney of Adult Services, and Joan Planell of Child Welfare Services, recruited Jacqueline Glover, Ph.D., Philosopher-in-Residence at Children's Hospital and Director, Clinical Ethics, George Washington University Medical Center, to function as the Committee's ethicist and trainer. The group made inquiries on a national level, searching for other non-institutional, community based ethics committees. Unable to locate any which could serve as a model for the committee in Montgomery County, the group looked to the medical and nursing home community for guidance.

Membership

The group interviewed and selected members with diverse perspectives according to racial and ethnic backgrounds, professional affiliations, and participation in the private and public sectors. The group also sought out community representatives, clients or potential recipients of service from the

Cont. on page 6

NETWORK NEWS

Cont. from page 5

Department, and Department staff. The initial Committee was composed of members from the public sector, including a physician, psychologist, nurse attorney, social workers and the director of the local area agency on aging. A rabbi, nurse, psychiatrist, and an ethicist represented the private sector. From the community, there were two representatives with family members who were eligible for services from the Department. There were 17 members in total.

Purpose, Guidelines, and Procedures

The first meeting of the committee was held in May 1991. Its initial task was to agree upon the Committee's purpose and ethical guidelines. With literature from medical centers and nursing homes throughout the country as reference, the Committee formalized its purpose and established general ethical guidelines. Of prime importance, the Committee was formed to act in an advisory role to the Department Director on the ethical, moral, and philosophical issues of client services, with a particular emphasis on those adults and children for whom the director holds guardianship.

The Committee also established procedures for referral of a case or policy issue. It is important to note that any staff member or individual may make a referral to the Committee. Staff members do not need supervisory or administrative approval.

Training

From May 1991 to April 1992, the Committee met once a month. Dr. Glover led the Committee in discussions of ethical theory and decision making. Committee members read and discussed many articles. In addition, Committee members as well as invited Department staff presented cases. During these retrospective case reviews, the Committee framed the issues within an ethical context and formulated recommendations that were within ethical guidelines.

Case Reviews

Since April 1992, the Committee has

conducted five concurrent case reviews. The first case was reviewed jointly with the Ethics Committee of the Children's National Medical Center in Washington, D.C. A six-month old child was under the care and custody, i.e., foster care, of the Montgomery County Department of Social Services and was hospitalized at the Children's National Medical Center. Through this collaborative effort, the two committees were able to come to a joint recommendation that was adopted by the Department Director and the hospital administration.

Three other cases involving children in foster care have been brought to the Committee in the past year. The ethical questions were substantially different; an issue of children placed in foster care with providers who practiced a different religion from the children's birth parents and wishes; a question of foster care placement which prioritized one foster child's needs over that of his sister's interests; and the need for medical consent for life-threatening surgery for a child for whom the Department Director was guardian. In the first two cases, the Director concurred with the Committee's recommendations. In the third, medical consent was not needed prior to the child's adoption and the Committee did not make a formal recommendation.

In the fifth case, the Committee was asked to review whether it was ethical to recommend a DNR order for an elderly gentleman under guardianship who was residing in a nursing home. The director concurred with the Committee's recommendations and the Circuit Court upheld the recommendation. However, the matter remains unresolved because the Court-appointed attorney who represents the client has appealed the decision.

Activities

During the last year, the Committee has conducted workshops and training sessions. In May 1992, the Committee provided training to Department staff on ethical principles and decision making. The role and function of the Committee was explained to the staff. During the summer of 1992, several Committee members spoke during a "brown bag"

lunch for leaders in the County's health and human services programs, explaining the goals and guidelines of the Committee. In October 1992, the Committee held a half-day training seminar for directors and senior staff of the local Departments of Social Services in Maryland, introducing ethical principles and case examples.

Submitted by
Jay Kenney, Ph.D.
Chief of Adult Services
Montgomery County Department of
Social Services

Case Presentation

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee in the region and how the committee resolved it. Individuals are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information of patients and others in the case should only be provided with the permission of the individual. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to: Editor, Mid-Atlantic Ethics Committee Newsletter, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201-1786.

Case Consultation in a D.C. Hospital

PRESENTATION: THE CASE OF MICHAEL:

Michael, a 2 year old boy, was admitted to the hospital for work-up of a lump on his back. The lump turned out to be a malignant tumor. Surgery was performed and all gross tumor removed; however, there was a strong possibility that microscopic residual tumor remained. Further studies also demonstrated evidence

of metastasis to the lungs and bone.

According to the Oncologist, Michael has no chance of survival without chemotherapy. With chemotherapy there is a 40% chance of a long-term, disease-free survival. The chemotherapy consists of cycles of three different drugs given intravenously for a period of about 4-1/2 months. The side effects of the drugs are nausea, vomiting, hair loss, hemorrhage and the possible need for transfusion, and depression of the bone marrow which could lead to increased risk of infection. One of the drugs can cause hearing difficulties in the high frequency range, but not in the frequencies needed for normal hearing. Another drug may produce kidney function abnormalities, which can be permanent.

For maximum benefits, Michael's physician recommends that chemotherapy be started within three weeks of diagnosis. However, the parents have not agreed to the treatment and there has already been some delay past this point.

The parents give several reasons for their reluctance to agree to treatment at this time:

1. They are uncertain about the real chances for a good outcome and want to gather more information.
2. A close family friend recently died of breast cancer after a long and difficult course of chemotherapy. They are concerned about Michael's quality of life on chemotherapy and the chance that he will suffer greatly and still die.
3. They believed that Michael's current nutritional state is poor, exacerbated by his extreme anxiety about being in the hospital.

The parents stated that if Michael was to receive treatment, they think it would be better to let him recuperate at home for some period so that he would be better able to withstand the chemotherapy. They further stated that it was their decision to make, not the doctors.

How should the ethics committee proceed in this case?

Case Discussion: Comments From A Law Professor

It is my assumption that Michael's physician would petition the Ethics Committee for direction on how to proceed with Michael's treatment, although any intervention of the Ethics Committee may be premature and unnecessary. According to the facts stated, Michael's physician is in a hurry to get started with chemotherapy within three weeks of diagnosis, although it is not clear how much time has passed since the initial diagnosis. It is further stated that there is a 40% chance of a long-term disease-free survival following four and a half months of intravenous chemotherapy. However, in addition to nausea, vomiting, hair-loss, hemorrhage, and the possible need for transfusion, serious side-effects include depression of the bone marrow, hearing difficulties and permanent kidney function abnormalities.

It seems perfectly reasonable that Michael's parents are reluctant to agree to this treatment without further clarification of the chances for a good outcome and additional information. It also seems perfectly appropriate for them to be concerned about Michael's quality of life on chemotherapy and the chance that he will suffer greatly and still have a 60% chance of no cure. Their expression of concern for his poor nutritional state while in the hospital also seems a legitimate concern as well as their belief that they want a time of recuperation at home prior to the chemotherapy. These are all concerns that the Ethics Committee needs to hear from Michael's parents in order to better understand their reluctance to go forward at this time.

Based on these legitimate concerns the Ethics Committee might first recommend an independent oncology consultation to either support Michael's physician or to raise additional questions that may need clarification prior to making a final

treatment decision. These concerns do not appear to be based on medical neglect in any way, but rather, a legitimate interest in more information and concern for Michael's quality of life. It is critical that Michael's parents not be pushed into a decision that they are not willing to support. Otherwise, they will be ill-equipped to provide Michael with the necessary psychological support, regardless of outcome. Certainly, based on the present facts, I would respect the parent's decision to defer consent to the treatment without more information. Parental autonomy and family privacy is a recognized legal and ethical interest. Although not absolute, it is our primary starting point. Clearly the state does have an interest in preventing the medical neglect of a minor child, but based on these facts, medical neglect is not apparent. Based on current law, a finding of medical neglect, and a court's decision to override the wishes of the parent would be based on the following factors: the severity of the condition; the need for immediate action; the benefits and risks of the proposed treatment; the alternatives to the proposed treatment, including no treatment at all; the preferences of the child where appropriate; the degree of conflict among medical professionals with respect to treatment options; and whether the treatment is deemed conventional or experimental. In a similar case decided by the Delaware Supreme Court, *Newmark v. Williams*, 588 A.2d 1108 (1991), the court held that a three-year old child with cancer was not neglected when the parents refused to accede to medical demands that the child receive a radical form of chemotherapy having a 40% chance of success.

The court stated:

No American court, even in the most egregious case, has ever authorized the State to remove a child from the loving, nurturing

Cont. on page 8

Comments From a Law Professor

Cont. from page 7

care of his parents and subject him, over parental objection, to an invasive regimen of treatment which offered . . . only a forty percent chance of "survival."

It would be my hope, in this case, that there would never be a threat of a medical neglect proceeding to force the parent to consent to the treatment prematurely. Rather, good medical practice is good ethical practice, and we should encourage open dialogue between Michael's physician and the parents. The parents have legitimate concerns that need real answers. In spite of the physician's urgency to get started, there are no short cuts to process. Regardless of the medical outcome, Michael's parents must feel that their concerns are being heard and that the process is fair.

Submitted by

Karen Rothenberg, J.D., M.P.A.
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Case Discussion: Comments From A Bioethicist

The central ethical question posed by Michael's case, "Are these parents ethically valid decision-makers for their critically ill 2 year old?" presupposes that there is some doubt about the parents' ability to provide an ethically valid answer to the question, "What is in this child's best interest?" The case as presented, however, does not include sufficient information for the reader to assess what is even medically in this child's best interest - perhaps because there is simply no way of knowing.

To work through this case, the Ethics Committee needs to gather ethically relevant medical and psycho-social data, paying close attention to how the information is marshaled and by whom. Committee members need to be meta-cognitive (i.e., thoughtful of one's own thinking), about their own ethical filters and attempt to understand the value frameworks of all ethically relevant parties. For example, the oncologist may see his/her recommendations in terms of a principlist emphasis on beneficence (Dugan, 1987). The child's parents may apply a more feminist ethics approach that translates into serious reservations about possible damage to the child's sense of security (Warren, 1992).

The ethically relevant medical information clusters around the percentage chance of long-term, disease-free survival for this particular patient and possible anticipated consequences of waiting. What is known from clinical experience and research data about this kind of cancer, with this rate of metastatic spread, in 2 year olds? On what scientific basis is this 40% prediction made? Is it a prediction based on statistical probabilities or on this particular child's changing clinical condition? How accurate can such a prediction be? How is this percentage prediction affected by waiting? How does the child's nutritional status impact long-term outcome? What evidence exists that three weeks is the appropriate outer-limit boundary for beginning therapy? What is the operative definition of long-term, disease-free survival? What are relapse rate expectations for this patient now, after successful treatment, or after partially successful treatment? What might be this child's prognosis after a relapse? Has a consulting pediatric oncologist reviewed the case?

Evaluation of the medical factors is essential to assure that where differences in opinion arise, they are scientifically justifiable differences of opinion. More philosophically, in evaluating the certitude of these factors for this particular child, committee members need to keep in mind the difference between hopefulness and sound evi-

dence. Even the best possible outcome, long-term disease-free survival and no relapse, assumes that this 2 year old will suffer from the side effects of the chemotherapy. One can only speculate about developmental or psychological harms this child might sustain.

At a minimum, Committee members need to remember that medicine is practiced in a climate of uncertainty. Jay Katz elegantly articulated this uncomfortable point in reference to physicians, but his wisdom speaks to all of us in the health care field:

Death...is not your enemy who needs to be defeated... We...experience great difficulty in accepting our impotence in the fact of disease and inevitable death. The enemy is our inability to accept the limits of what we can do. (Katz, 1991, p.695)

Nonetheless, someone has to act for this child - or be allowed not to act.

Given that the oncologist wants to treat, a position consistent with the value of supporting life, it seems reasonable to conclude good faith on his/her part. But why is there a question about the parents' authority to make the final decision? The Committee must ascertain what is driving the parental delay.

Do the parents understand their child's medical condition and the possible consequences of treating or not treating? Is the nutritional issue a smoke-screen for hidden problems or fear? Are there psychiatric or psycho-social factors impeding the decision-making process? Are there cultural, racial, ethnic or socio-economic barriers to communication between the parents and health care team? Are there personality problems between the parents and the physician? Do these parents have religious or cultural beliefs that might be effecting their decisions? If so, are these beliefs well considered and consistent or magical and erratic? Are the parents feeling overwhelmed by financial or other anticipated burdens?

In the end, if the Committee assures itself that there are no nefarious subtexts, no cloudiness of thinking or communication, that these parents are acting in good faith and are honestly trying to ascertain what is in the best interest of their sick child, they ought to be affirmed as the ethically valid

decision-makers. Hesitancy, or refusal, to treat this child is not sufficient, in and of itself, to shift the ethical responsibility away from the family.

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Submitted by
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Implementing The PSDA - Some Reactions

The following two articles are based on experiences of a number of institutions with implementation of the Patient Self-Determination Act. The first focuses on the reaction of nurses at one hospital to the role of asking patients whether they have an advance directive; the second, on the experience of nursing homes in Maryland in implementing the federal law.

Nurses' Perspectives On Their Role to Implement The PSDA

The goal of the Patient Self-Determination Act (PSDA), which went into effect on December 1, 1991, is to enhance patients' control over medical treatment decisions by promoting the use of advance directives. This Act requires health care providers to ask patients whether they have prepared advance directives and to provide patients with written information about advance directives.

Health care facilities have enormous latitude as to how they implement the PSDA. One aspect of a hospital's program to implement the PSDA involves the assignment of who is responsible for initiating discus-

sions with patients concerning advance directives. Informal surveys have shown that admitting clerks, patient representatives, nurses, and, to a lesser degree, house officers, have been given primary responsibility for this task.

In a hospital where nurses were given a significant role in the implementation of the PSDA, we interviewed twenty nurses from four different ward services in order to determine how nurses perceive their role in the implementation of the PSDA and how prepared they felt to undertake this role. The ward services included a medical unit, a surgery ward, a trauma unit where outpatients who had recently experienced traumatic injuries were readmitted for same-day procedures, and a progressive coronary care unit where patients consisted of those transferred from the coronary care unit or were awaiting elective cardiac procedures.

Most of the nurses expressed a favorable reaction to being involved in the hospital's advance directive program. Reasons for feeling positive about the program included the potential to: 1) enhance patient autonomy, 2) prompt patients to think and talk about end-of-life decisionmaking, 3) enhance discussions between patients and their families and their health care providers, and 4) provide information to patients about advance directives.

Most of the nurses also felt qualified to ask patients whether they had prepared an advance directive. In order to minimize patient anxiety when asking about advance directives, nurses developed several strategies to make the inquiry less threatening. These strategies included telling the patients that they were required by "law" to ask this question, incorporating the question into the normal nursing admission routine, and providing examples of how an advance directive can preserve patient autonomy if the patient becomes unable to make medical decisions.

Several nurses, however, wanted to do more than what was required of

them. Specifically, nurses felt that because of the nature and strength of their relationship with patients they had a moral obligation to educate patients about advance directives. Unfortunately, several obstacles existed that prevented nurses from adequately fulfilling this duty. These impediments included: 1) not having received the proper knowledge on advance directives and 2) not having the proper amount of time during the admission process to adequately talk to patients about advance directives.

Hence, although most nurses have a favorable reaction to being involved in a hospital's advance directive program and consider their role as a moral obligation, lack of education and time prevents the successful discharge of this duty. Hospitals need to be aware of nurses' interest in implementing the PSDA and provide the necessary environment to foster this interest. Attention to such matters can better enhance the goals of the PSDA.

Submitted by
Henry Silverman, MD;
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Niti Armingier

Implementation of the PSDA in Maryland Nursing Homes

A survey of nursing home administrators reveals great variation in how the Patient Self-Determination Act (PSDA) is being implemented in Maryland nursing homes and widely differing percentages of nursing homes residents who reportedly have advance directives.

In addition, almost half of the administrators responded that some of their staff have raised ethical concerns about implementing some advance directives.

"The Patient Self-Determination Act is definitely a step in the right direction, but these findings suggest a need for more education of nursing

Cont. on page 10

Implementation of the PSDA in Maryland Nursing Homes

Cont. from page 9

home administrators and staff about the legal and ethical aspects of decisionmaking for nursing home residents," said Marjorie Richmond, supervisor of Public Guardianship for the Elderly in the Maryland Office on Aging and a study collaborator. The survey was conducted by nursing home ombudsmen through the Maryland Office on Aging, and the preliminary findings are based on returns from 70 percent of Maryland nursing homes.

The PSDA requires healthcare providers to inform competent adult patients of their right to execute advance directives under state law, and to ask patients at admission if they in fact have advance directives. The law gives health care facilities great latitude in fulfilling its requirements, a fact reflected in the survey findings. For instance, among Maryland nursing homes, the person charged with the responsibility for discussing advance directives with residents at admission varies from social workers in 38 percent of the facilities, to admission clerks in 27 percent,

nurses in 5 percent and physicians in 6 percent.

Also, while there was written documentation of a patient's treatment preferences in 97 percent of the facilities, the specific treatment decisions routinely discussed varied: 92 percent of the facilities discussed resuscitation in the event of cardiac arrest; 68 percent discussed breathing with a respirator; 81 percent discussed artificial feeding; 53 percent discussed treatment of infections with antibiotics, and 77 percent discussed transfer to a hospital.

Nursing homes also differed in whether and how often advance directives were routinely reviewed with residents and/or their surrogates. While 46 percent of the facilities review advance directives at regular intervals (ranging from 3 to 12 months) and about 45 percent review advance directives when patient health changes (18 percent review regularly and when health changes), 27 percent of nursing home facilities do not review advance directives after the initial discussion with the resident at admission.

Perhaps the greatest variation, however, was seen in the estimates of the percentage of residents in each

nursing home that have advance directives: 2.6 percent of facilities reported that 100 percent of their residents have advance directives; 28.3 percent of the facilities reported 75 percent of residents have advance directives; 21.1 percent of facilities responded that 50 percent of residents have advance directives; and about 20 percent of the facilities reported that 10 percent or less of residents have advance directives.

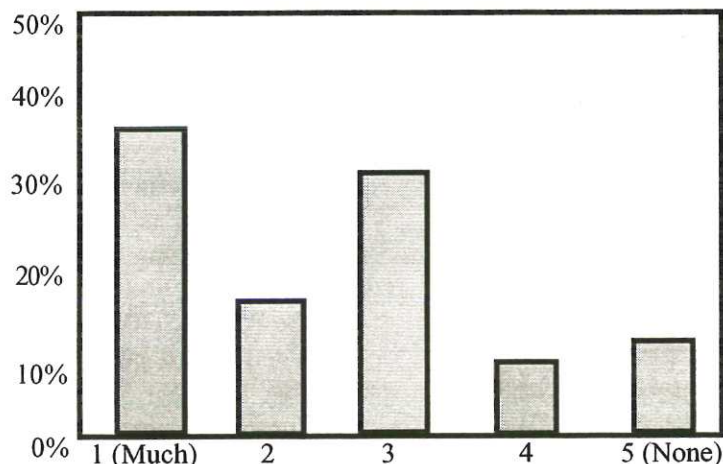
The PSDA's effect on the number of nursing home residents choosing advance directives was also evaluated. When asked what was the best estimate of the number of patients, within the last six months, that have executed an advance directive as a result of being asked at admission, administrators' responses also showed a great range" from 5.3 percent (8 facilities) reporting 100 percent of patients choosing to execute advance directives, to 30 percent (45 facilities) reporting 5 percent of new residents or less.

As to why some nursing home residents do not execute advance directives, 62 percent of administrators said that patients and/or surrogates do not want to discuss them because it is uncomfortable; 59 percent said patients and/or surrogates do not understand them; 30 percent said admission to nursing home is the wrong time; and 14 percent said health care professionals are uncomfortable discussing them with patients.

The survey also attempted to measure administrators' attitudes toward advance directives and the PSDA. "Although we're still in the process of analyzing the data, a preliminary multiple regression model does confirm a positive relationship between administrators' attitudes toward advance directives and both the percentage of residents in their facility with advance directives and the percentage of residents who execute advance directives on admission," explained Ruth Gaare, a graduate student at Johns Hopkins School of Public Health who designed the study.

Nursing Home Administrators' Responses, by percentage, to the following statement:

PSDA has had an effect on process of decisionmaking



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CALENDAR OF EVENTS

May

May 20th

NIH Bioethics Journal Club. Topic: "Ethics of Vaccine Trials." 3:30 - 5:00 p.m., Bldg. 10, Room 2C-116. For more information call John Schumacher (301)496-2429.

May 25th

Metropolitan Washington Bioethics Network Meeting, 4:00 - 6:00 p.m. District of Columbia Hospital Association, 1250 I St., NW, Topic: "When is Treatment Futile: Religious Conflicts over Terminal Care." Contact: Joan Lewis (202) 682-1581.

May 27th

Lecture by Kevin Wildes, S.J., Ph.D., Editor of the Journal of Medicine and Philosophy; Center of Ethics, Medicine and Public Issues; Baylor College of Medicine; "Advance Directives in Health Care: Lessons in Finitude." 4:00 - 6:00 p.m., Loyola College of Maryland. For more information call Janet Penn (410) 617-2107.

June

June 3rd

Workshop on "Evaluating Your Ethics Program Performance." The Jefferson Hotel, Richmond, VA 4:00 - 8:00 p.m. Contact: Bette Kramer (804)287-7450.

June 3rd

Baltimore Area Ethics Committee Network Meeting, 4:30 - 6:30 p.m. University of Maryland Medical System. Topic: "Health Care Decision-making for Infants and Children." Contact: Henry Silverman (410) 706-6250.

June 4th-5th

The 14th Annual Health Law Teachers Conference -- a conference designed for professors of health law and bioethics. University of Maryland School of Law, Baltimore, MD. Sponsored by the American Society of Law, Medicine & Ethics. For a conference brochure call (617)262-4990.

June 22nd

Washington Metropolitan Bioethics Network, 4:00 - 6:00 p.m., Walter Reed Army Hospital; Topic: "Problems in Surrogacy." Contact: Joan Lewis (202) 682-1581.

July

July 27th

Washington Metropolitan Bioethics Network, 4:00 - 6:00 p.m., Washington Home & Hospice; Topic: TBA. Contact: Joan Lewis (202) 682-1581.

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